

# dis-Abilities Celebration Connection

**SUMMER 2011**

## *Summer ~ a time for looking back and planning ahead*

**M**any families spend the summer relaxing by the pool, taking vacations and scanning the Sunday paper for back-to-school sales. Summer is a great time for thinking about the successes – and failures – of the year just ended, and the exciting – and scary – challenges that lay ahead.

I know something about looking back and planning ahead. For me, the past three summers have been spent undergoing and recovering from three major surgeries. In the winter of 2006, I began to notice that walking was becoming more and more difficult. By the Fall of 2007, I was using a cane nearly all the time. Eventually, I was diagnosed with spinal stenosis and osteoarthritis.

The first surgery in 2009, was a laminectomy and spinal fusion, and was extremely nerve-wracking to think about. I planned ahead as best I could, researched various assistive devices to help with my recovery, and made arrangements to work from home. Friends and family were, of course, wonderful, sending flowers, visiting and bringing pre-made dinners.

The second surgery last year was a total hip replacement. I remember feeling much more prepared and less anxious. Friends and family were still solicitous about my welfare, but there were fewer flowers, cards and visits.

This summer, I underwent the second hip replacement and am in recovery now. The anxiety of the first surgery was almost totally non-existent. Friends, who were so worried about me the first time, took this latest (and hopefully last!) surgery in stride. They seemed to be sure that I would be able to get through it just fine. They were right; I have become a

surgery expert! With each successful operation, I have transitioned a little more easily to being able to walk unassisted.

So what does my story have to do with anything? Just this – families who have children with special needs go through many transitions. The first time their child ventures out from the safety of home to preschool or kindergarten is nerve-wracking. Parents plan ahead as best they can, by doing their research and talking to school officials and other families who have had similar experiences.

Another important transition is from elementary to middle – or junior high – school. But by now, the family has hopefully developed several essential support systems, and has had some important successes and failures from which to learn valuable lessons about how to be better prepared for the next transition – high school.

The transition to high school is a turning point in many ways. Along with parents, who may have by now, become transition experts, their child can and should be participating in the planning stages of this most important transition of all – the transition to his or her own adult life.

So while you're hanging out at the beach and backyard barbecues, take some time to think about and plan for the next transition in your family's life. And do your best to take it all in stride. You'll find that becoming an expert is almost inevitable.

*Laura Nelson*  
Editor



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# Relaxing in Savannah

By Carrie Smoot

The idea for the trip started about a year and a half ago, when my aunt saw a magazine article about Savannah, GA, as a vacation destination. "It sounds nice, but it may not be that accessible," she said. I admired the photos of the historic houses, but wondered if we should go through with this....

Eventually, our desire to see a different area of the country chased our doubts away, so we spent a week there in June. When people visit new places, they want to know its history—what makes it unique—and perhaps do more research on arriving home. One of Savannah's biggest draws is its historic district. We wanted to see a lot in that area, and stay at a nearby hotel.

The City of Savannah is laid out in squares, with a lot of public parks, outdoor sculptures, historic buildings and museums to enjoy. While it is easy to navigate the sidewalks and brick paths by wheelchair, make sure that everyone with you can handle the walking distances. When we started talking about the trip, I was only familiar with the Juliette Gordon Low Birthplace, since I was in the Girl Scouts. That would certainly have a spot on our itinerary, if we could fit it in.

## Planning the Trip

We checked out travel guides from the library and began online research. Take a small Savannah guidebook along, such as Frommer's or Fodor's, if possible. Never feel obligated to follow the guide to the letter, but it is helpful to have information handy, even though these books might not have a great deal of disability-specific travel information. It didn't hurt to read John Berendt's *Midnight in the Garden of Good and Evil*, the book—and later, film—that made

Savannah famous. Watching *Forrest Gump* can also put you in the mood for the city.



The best guide, however, is the *Accessibility Guide to the Historic District*. The latest edition is Fall 2010, and it contains information on accessible tour options, accessible museums and historic sites, historic houses of worship, restaurants and more. A map of the historic district was also included. We wore our Guide out, and selected far more activities than could be completed in one trip. The Savannah-Chatham Council on Disability Issues is most likely to have the absolute latest edition. They are also available by mail from the Savannah Visitor Information Center, who also publishes a separate visitor's guide.

First, we planned for the hotel and train—requesting Amtrak's accessible Room H—and transportation once we got there. For the first time, I would be using my power wheelchair, riding in my manual chair only as a backup. We rely on accessible cabs when traveling. We learned early that there was only one accessible taxi for the entire city, provided by Yellow Cab of Savannah, so we wanted to use paratransit within the

City as well. Several phone calls between WMATA and Savannah's Teleride system to get them my paperwork allowed us to use these services for a couple of rides. Buses in Savannah have fold-out ramps instead of hydraulic lifts. The CAT (Chatham Area Transit) system operates a free shuttle, along with free Dot downtown shuttle transportation and paid bus routes. CAT also operates a streetcar along River Street, and two ferries that travel between the convention center and River Street.

## Favorite Spots and Activities

After years of seeing Old Town Trolleys in Washington, DC, I finally rode one in Savannah. We were lucky enough to book an afternoon accessible tour that first morning. Although with accessible tours, people in wheelchairs can't get on and off, the driver keeps everyone entertained with jokes and local stories, pointing out all the landmarks. Many people visit Savannah for the architecture, and the buildings are very pretty. A bus tour is a great way to see all of the historic area.

The Ralph Mark Gilbert Civil Rights Museum is a must-see for everyone. It chronicles Savannah's role in the civil rights movement of the 1950s and 1960s, and is very moving. You learn about other people's experiences during that time. It's not only modern history, but earlier history as well. Tours are self-guided, but staff members are great with tour groups and are open to people's questions. The museum is named for Rev. Ralph Mark Gilbert, civil rights leader and the pastor of the First African Baptist Church, historic in its own right because it was built by and for slaves. It is located in Franklin Square, near our hotel.

We were very close to City Market, adjacent to Ellis Square, and spent a lot of time in its shops, restaurants and galleries. This is the place where everyone gathers to meet with friends, walk their dogs, listen to local musicians, or take a horse-and-buggy ride through the historic district. While we enjoyed outdoor dining in the hot weather, some establishments keep portable ramps handy in case wheelchair users need help entering the restaurant. All you need to do is ask.

Ellis Square has a lovely ramped public fountain and benches where people can stop and rest, or cool off in the fountain. Nearby is a statue of favorite son Johnny Mercer, and many a tourist poses by it.

And if you want to spend time outside the city awhile, go to Tybee Island, the beach and boardwalk. Take time to visit the Tybee Island Light Station and Museum ([www.tybeelighthouse.org](http://www.tybeelighthouse.org)). The lighthouse is awesome! The museum and other portions are not accessible, but it's still a peaceful and fun day outdoors. The second floor of the assistant lightkeeper's cottage is accessible, and the orientation center, which outlines its history, is accessible, along with the gift shop. Nearby local restaurant The Crab Shack is right on the water. They serve a tasty Low Country Boil.

If you're hungry for down-home southern cooking and new twists on modern dishes, Paula Deen's hugely popular restaurant, The Lady and Sons, is the place to be. It's not too far from Ellis Square, on Congress Street. But get there early, in person, by 9:30 a.m. to reserve a time the day you want to go. Bring an empty stomach.

River Street is another vibrant shopping and dining area in Savannah. Not all of the stores are accessible, but employees will be glad to assist if needed. Cobblestone is extremely rough on any kind of wheelchair, so stay on brick paths when you can. If sitting by the water and watching its rhythm and the various the boats is your thing, get on the brick path along the river, where there are many trees, park benches, and vendors. Riverboat cruises leave from here as well.

If you like art, the Telfair Museums and the Savannah College of Art & Design (SCAD) Museum have lots of exhibits if

## *A Few Things to Be Aware of*

As of this writing, the Amtrak train station in Savannah does not have accessible restrooms at all. Renovations are planned at some point, according to a conversation I had with one of the employees. Perhaps, through letters from residents with disabilities and tourists, the situation will improve in the near future.

Many people with mobility challenges—and even those who get around well—have considerable difficulty getting up onto the very high beds in accessible hotel rooms. Since I couldn't get on it at all, even with help, I asked the hotel staff if they could do something to fix it. The engineer removed the bed frame, which lowered it about 10 inches. The next time I go anywhere, I will ask for these options when making reservations.

And everyone knows that transportation doesn't always run smoothly. We discovered that some of the Dot vehicles are not always well maintained, and other snafus can happen. When they happen, be sure to unpack your sense of humor.

Once we returned home, we were already thinking of going back again at some point. The

warmth and friendliness of the people stay with you, as well as Savannah's slower pace. Whatever you are looking for in Savannah, you will find it. ■



you have the time. SCAD closed for renovation the week before we visited, but should reopen in the fall.

## **Links:**

- *Savannah-Chatham Council on Disability Issues* – [www.savannahchathamdisability.org](http://www.savannahchathamdisability.org)
  - *Visit Historic Savannah* – [www.visit-historic-savannah.com](http://www.visit-historic-savannah.com)
  - *Savannah Visitor Information Center* – <http://savannahvisit.com>
  - *Savannah, GA, City Guide* – [www.savannah.com](http://www.savannah.com)
  - *City of Savannah Visitors Home Page* – [www.savannahga.gov/cityweb/SavannahGaGOV.nsf/mainportal/visitors?opendocument](http://www.savannahga.gov/cityweb/SavannahGaGOV.nsf/mainportal/visitors?opendocument)
- The Accessibility Guide to the Historic District is available in PDF format on this site.

Photos courtesy of [www.historictours.com/savannah](http://www.historictours.com/savannah)

# LIVING LIFE AGAINST THE CURRENT

By Carrie Smoot

I first learned of Robert Segalman's 2009 autobiography, *Against the Current: My Life with Cerebral Palsy*, while writing the social media story in the Spring Issue of this newsletter. I enjoyed it so much that a separate article seemed appropriate. Dr. Segalman was kind enough to participate in an e-mail interview. Read his responses below.

The quality one notices immediately about Dr. Segalman is his supreme confidence. Many of his experiences will resonate with readers, and he is candid about some topics. His life is typical. He grew up with loving parents and a younger brother and sister, went to school, dated and had lots of friends. He has also enjoyed marriage.

Education was prized in his family. It was a foregone conclusion that he would go to college and then graduate school, living independently in different areas of the country. Eventually, he earned a Ph.D., and now holds an honorary doctorate. He has worked at several jobs—at a time before the ADA, when terms such as accessibility, inclusion, and reasonable accommodations were not well known and were not standard practices. He learned that it was okay to speak up, to ask for things.

Segalman uses a power wheelchair and works with personal care attendants. A major frustration, though, is that his speech is severely affected and using the telephone is difficult. Whenever possible, he meets these situations with humor. The frustration led him to found Speech-to-Speech, a national, toll-free service where trained communication assistants make telephone calls for people who have speech disabilities, repeating their words exactly in a three-way calling environment. Learn more at [www.speechtospeech.com](http://www.speechtospeech.com).



**1)** How would you update *Against the Current*? What is your life like now? Where can someone buy the book?

If I were going to update my book, I would give more advice about sexuality and CP because I have more information about that now. The book can be purchased at [www.drbobsautobiography.org](http://www.drbobsautobiography.org). Free PDF copies are available for download at the website.

My life is now probably less stressful than it has ever been. That is because I am single and retired. I devote myself to improving telephone access for people with speech disabilities. I am working to persuade the FCC to approve a form of Speech-to-Speech that would include a video component. The video component will allow people who need to be seen to be understood to use the telephone. Working for the state was stressful for me because speech disability is at the bottom of the disability hierarchy in that agency. It was difficult to persuade the department to devote resources to a speech disability project.

My life is also less stressful because I became single several years ago. I am devoted to my cause and it is difficult for me to put the needs of a spouse before my cause. Several years ago, I also quit driving. Driving was difficult for me because it took so much concentration. I live downtown, where almost everything is in walking distance.

Another change [that] has reduced my stress is my decision to avoid the public. Whether I like it or not, my disability makes me a public figure. People feel free to ask my companion all kinds of questions about my personal life that they would

never ask an able-bodied stranger. Many people assume that because of my significant CP, I am also cognitively impaired. Having to prove to them that I am cognitively sound becomes a burden when I have to do it frequently. Email allows me to work on my goals without having to deal with the public directly.

**2)** What is happening now with Speech-to-Speech as an organization? How much more is the service being used internationally?

Speech-to-Speech (STS) is a service, while Speech Communications Assistance by Telephone is an organization that I manage to protect the telephone rights of people with speech disabilities and promote STS. The STS service is now available 24/7 nationwide and in Sweden, Finland, Australia and New Zealand. The challenges are outreach and quality of service. The federal regulations for STS are modeled on the TTY Relay. Unfortunately, the speech-disabled community does not have the resources of the deaf community. We cannot advocate in the way that the deaf can. This lack of advocacy makes outreach and quality of service difficult. This phenomenon is compliment to the deaf community, who have been our model in building accessible telecommunications.

**3)** Do you find that many more people with speech disabilities are aware of this national telephone relay service and use it regularly? Do you find that the same barriers you spoke of early in the book still exist? Why or why not?

The under-utilization of STS described in the book still exist, but since I wrote the book, I have developed the following explanation for that underutilization. We estimate that about 1 percent of the people who could use STS know that it exists. Under-utilization is measured by the number of calls made. The low call volume results from a poor financial structure within the states, which is a major barrier to STS's success. The deaf have similar problems with traditional relay because much of the funding comes from the states. The deaf solved that problem with Video Relay because all the funding comes from the FCC. We hope to mimic the deaf solution by making Video Assisted STS financed by the FCC.

**4)** Do you think that people with speech disabilities fear using the telephone, or is it just the frustration of not being understood by other people? If it is fear, how does someone get over it?

It is both fear and frustration that prevents people with speech disabilities from using the telephone. There is a chicken and egg problem because the frustration leads to fear and the fear can cause even more difficulty in speaking and that difficulty increase the fear and increases the frustration.

**5)** How are communication assistants trained to relay phone calls? Is a lot of it intuitive—just listening carefully and focusing their full attention on the people having the conversation? How are users of the service trained as well?

The way I designed the training a decade ago included training of only people with excellent hearing and language processing skills. I spent a whole day teaching them the dynamics of the speech-disabled population. I also made many demonstration STS calls for them during the day and had them critique the operator's performance. At the end of the day, I asked each of the operators to put an apple in their mouth and make a Speech-to-Speech call so that they would develop a better understanding of the consumer's situation. After a year of my training operators, the phone companies took over the training and made the training information proprietary, so I don't have the current training information.

Lack of training opportunities for potential users is a primary reason for under-utilization of STS. The law requires the FCC to provide the service, but not the training. Many consumers have never used the telephone before. Family and caretakers have made the calls for them and have a vested interest in maintaining that power over the consumer. A skilled trainer needs to alter those dynamics to increase STS usage and make sure that the consumer develops the social skills necessary to use STS and acquire the necessary equipment such as a speakerphone or a headset. We have many examples of ongoing STS use resulting from three one-hour training sessions by Speech-Language Pathologists and other allied medical professionals.

**6)** Please elaborate on the technology you use, such as AAC? (Is this also called augmentative communication?) Is this required to use STS? What technology is needed?

The AAC device is set next to a speakerphone so that the output of the device becomes the input of the telephone. This configuration allows me to use STS when I don't have an assistant available to revoice for me.

The technology used by STS consumers includes headsets for people unable to hold the telephone. Speakerphones are also used for the same reason. Many STS users have brain damage, which impacts manual dexterity and speech. Some consumers use speed dialing to circumvent dexterity limitations. Other consumers use Augmentative and Alternative Communication (AAC) because their speech is too difficult for the operators to understand. AAC often consists of a laptop with voice-output allowing the consumer to type in the anticipated text before each call.

**7)** Do you think computers and email, social media, cell phones, BlackBerrys and other PDAs are better than the phone? Why or why not? Are these devices accessible, in your opinion?

All the technology that you mention [is] useful to some people with speech disabilities. This technology is not useful to that portion of the speech-disabled population who have dexterity and/or cognitive barriers to using such technology. Because poverty is rampant in the speech-disabled community, many of these people do not have access to the technology.

**8)** Please elaborate on your views about independent living. What are your specific tips about hiring personal care attendants or helpers?

Independent living is the key to physical and mental health for me. I am innately bossy and need helpers who can take direction from me. An independent living situation can be structured to allow directions from the consumer. I have never seen an institutional setting with such a configuration. The economic and administrative welfare

and the perpetuation of the institution come before the welfare of the consumer. I cannot think of an institutional setting that provides as much opportunity for optimum mental and physical health of the consumer. Economic factors prevent such opportunities.

Considerations in hiring helpers include: (1) ability to do the physical tasks required, (2) willingness to take direction from someone with a significant disability. For many potential helpers, this willingness is counterintuitive. (3) the ability to be on-call and live close enough to the consumer to get there quickly, (4) the emotional stability to handle the job, (5) ability to do necessary tasks that other helpers are unable to do. One helper may be good at lifting. Another helper may be good at revoicing what you say for people who cannot understand you. Another helper may be good at computer tasks.

**9)** Any additional thoughts on building a social life generally?

People with speech disabilities are all different and I can only speak for myself. The techniques that I use include: (1) scheduling visits in quiet areas where I can be easily understood, (2) choosing friends with good hearing, (3) taking the initiative to reach out to potential friends, (4) choosing friends who are comfortable with my disability and my lifestyle, (5) making good use of e-mail, Facebook, and singles ads to build friendships, (6) joining a church or similar social group, and (7) selecting friends who I can be with without transportation barriers.

**10)** How would you advise someone if they wanted to get a doctorate? Not all professions require them. How would you advise them on planning and preparing for this degree program? Is extra education worth it? Why or why not?

I only know how to plan for necessary education based on my 1960's experience. That said, if I were going for a doctorate again, I would: (1) choose a university in a climate which would not be impacted by my disability or do graduate work

online, (2) choose a career path that is not impacted by disability, (3) be overeducated. If you want a job that requires a BA, get a Masters. If you want a job that requires a Masters, get a Ph.D. Employers are often willing to overlook a disability if you have more education than other applicants, (4) choose a major in which you excel in competition with others in your class. Professors are more willing to overlook your disability if you are an A student than if you are a C student. Professors can discriminate against you intuitively because of societal values. Excelling academically is counter-intuitive to these values and may help you get the better grades, (5) choose a major in which there are jobs available and in which you have a strong interest and ability. This could be a problem in a constantly changing job market, because the major you choose at the beginning of your graduate school education may not continue to have employment opportunities after you graduate.

Choosing a career which meets all these requirements may be tricky or even impossible, (6) read the small print on all your medications to be sure that the side effects are not impacting your health and your academic performance. Don't count on doctors to do this for you. They can be strongly influenced by the detail people who often show up on their office doorstep in high heels and miniskirts to promote their employers' product. While that product may not be the best medicine for you, doctors (often male) may be so influenced by the appearance of the detail people that your health may not be the doctor's highest priority.

## 11) What are your thoughts on achieving career success?

I can only talk about my personal career success. All the jobs that I applied for required only a Masters, and my Ph.D. opened many doors. We all second-guess ourselves, but if I could do it over again I would have developed an additional skill that other job applicants did not have. For example, if I had gotten a law degree to go along with my Ph.D., I might have been able to obtain an academic appointment because I would be competing against people who only had a Ph.D.

Choose a career in which you will have all the advantages, such as climate optimization, described in the previous question. Choose a career in which you have such a strong interest that you won't mind making an extra effort to perform better than your peers. Again, this is a mechanism to compensate for the innate discrimination that many supervisors and other people have.

Make sure that advancement opportunities will not be impacted by your disability. For example, avoid careers that will eventually require relocation to a climate [that] could be negatively impacted by your disability.

Choose a career in which your values are similar to those of your employer. For example, my first job was in an institution for developmental disabled people. I did not know before I took the job that the primary goal of the institution was to perpetuate itself and avoid antagonizing the press or the state officials who oversee the actions of the executive director. The welfare of the patients came second. This was stressful for me because many of the patients had Cerebral Palsy and were not given opportunities to succeed because of institutional priorities.

In another job, I worked for a cross-disability government agency [that] was strongly influenced to give budget priorities to the consumers with certain disabilities. These were the same disabilities as those most strongly represented by lobbyists in the state legislature. ■

*Carrie Smoot is a Northern Virginia freelance writer.*

*All proceeds from the purchases of **Against the Current** benefit the 501(c)(3) organization, **Speech Communications Assistance by Telephone, Inc.***

# The U.S. Department of Education Rates Virginia on Implementation of Individuals with Disabilities Education Act

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*For Immediate Release July 12, 2011*

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The U.S. Department of Education (USED) in June rated Virginia and other states on their implementation of Part B of the Individuals with Disabilities Education Act. The reviews were based on annual special education performance reports for 2009, state performance plans and other publicly reported information and data.

USED praised Virginia for its efforts on 12 of 20 indicators related to the state's success in improving the educational outcomes of students with disabilities. Virginia, however, received an overall determination of "needs assistance" based on an indicator related to the review of local policies, procedures and practices in school divisions with significant discrepancies in the discipline on disabled and non-disabled students.

Specifically, USED cited the commonwealth for not reviewing the policies, procedures and practices of all divisions with significant discrepancies in the long-term suspension and expulsion rates of disabled and non-disabled students, and therefore, not reporting on the number of divisions with policies, procedures and practices that contributed to a discrepancy.

The June determination letter from USED's Office of Special Education Programs, however, noted that the Virginia Department of Education has submitted a plan to address the deficiency and that the commonwealth reported "valid and reliable" data for all other indicators.

The letter further praised Virginia for its efforts toward meeting goals in its State Performance Plan in the following areas:

- Disproportionate representation of racial and ethnic groups in special education as a result of inappropriate identification;
- Timeliness of initial evaluation of children for special education services;
- Transitioning of toddlers in need of special education services into the public school system;
- Providing supervision and correcting problems in school division special education programs;
- Resolving complaints in a timely manner;
- Adjudicating due-process complaints in a timely manner; and
- Collecting and reporting valid and reliable data about the education and performance of students with disabilities.

*IDEA, which was reauthorized by Congress in 2004, requires states and school divisions to ensure that children with disabilities receive educational services that meet their educational needs and prepare them for further education, employment and productive lives. IDEA also requires states to establish targets in their annual State Performance plans for achieving the objectives of the law.*

# PEOPLE WITH DISABILITIES AND EMERGENCY PREPAREDNESS



By Carrie Smoot

With National Emergency Preparedness Month happening in September, it's a great time for people with disabilities to think about the plans they have in place in case of emergencies. Will neighbors, family members, or friends be driving them to shelters and other locations, or will they stay where they are? How would they evacuate safely? Do they have enough food, water, medicines, and other supplies? It's also a good time to find out what local jurisdictions are doing to better serve people with all types of disabilities during disasters. See [www.ready.gov](http://www.ready.gov).

"There's been greater awareness in making emergency preparedness much more inclusive. We're concerned about meeting the needs of everyone who has a disability or access and functional need such as pregnant women, older people, the homeless, and so on," says Linda Landers, Regional Disability Integration Specialist with Region III Federal Emergency Management Agency (FEMA). Her office maintains a newsletter, and shares information with emergency managers, persons with disabilities, and the public.

"There's a real desire from people with disabilities to be involved in the planning. We are reaching out to all the disabled community and working with Independent Living Centers across several states to conduct trainings and get opinions and ideas from people with disabilities." Landers also notes an emergency preparedness conference coming up in Washington, DC, September 12-14, 2011, entitled *Engaging the Whole Community: Promising Practices in Inclusive Emergency Management*. For details visit [www.fema.gov/about/odic](http://www.fema.gov/about/odic).

## MAKING A PLAN

Bruce McFarlane is the Inclusive Emergency Planner of Fairfax County's Office of Emergency Management. If, in the event of a large disaster, firefighters, police, and Emergency Medical Technicians (EMTs) do not have the resources to deal with the incident, his office oversees getting supplies and help, such as food, water, shelter and or front-end and back-end loaders, trucks and other equipment, to the people who need it. He says that Fairfax County is one of the better prepared areas in the nation for emergencies, noting the experienced large workforce and the expanded 911 call-center. This past June, with a federal grant from FEMA, his office completed [www.ReadyNOVA.org](http://www.ReadyNOVA.org), a website that includes accessible family and business emergency plans. In the fall, his office will work with people with disabilities about participating in full-scale disaster drills and simulations so that first responders learn how to help and assist people with access and functional needs during emergencies.

"In a disaster, people have to 1) make a plan; 2) stay informed using the Community Emergency Alert Network (CEAN) through real-time text, emails or voicemails about weather, traffic, or emergencies; and 3) prepare an emergency kit for your home, at work, and in the car," McFarlane says. He encourages everyone, particularly people with disabilities, to sign up for CEAN at [www.fairfaxcounty.gov/cean](http://www.fairfaxcounty.gov/cean), and notes that the CEAN services are free.

McFarlane encourages Fairfax County residents with disabilities and serious medical issues to sign up on the Medical Needs Registry, available at [www.fairfaxcounty.gov/specialneeds](http://www.fairfaxcounty.gov/specialneeds).

There is also a Social Needs Registry for advocacy organizations at [www.fairfaxcounty.gov/specialneeds/socialneedsregistry.htm](http://www.fairfaxcounty.gov/specialneeds/socialneedsregistry.htm). "It's important to let people know of your needs and get that information out there," he says. "Right now, 90 percent of communities across the country do not have a medical needs registry. Besides Fairfax County, Norfolk and the Tidewater area maintains a registry, as does the State of Rhode Island and parts of Florida." The information that residents enter into the Registry is kept strictly confidential and used only by responder personnel (fire, police and emergency medical) during times of emergencies.

## PREPARING FOR A DISASTER

Chander Jayaraman of the Inclusive Preparedness Center in Washington, DC, says preparing an emergency kit isn't anything to worry about. "You don't have to get it together all at once," he says. "Just be on the lookout for sales of canned foods, water, Band-Aids, a hand-cranked radio and flashlight and batteries, and other items when you're out shopping. Also have extra medicines on hand, and copies of your important identification and medical papers. Once the kit is complete, store it within easy reach, such as a corner of your home or apartment."

But what's even more critical, he says, is having an emergency plan. Jayaraman often works on this issue, individually and in groups, with people who have disabilities. The Center also encourages emergency managers to work with local service providers to identify people with special needs, since these organizations would have the most current contact information.

"You have two choices—to shelter in place, or get out," he says. "Get to know your neighbors so that they can help you if you need it. Know at least three escape routes in case someone is helping you get to a local shelter. And if you live in a condo or apartment, inform the front desk of your needs. Get on their 'evacuate first' list."

The Community Emergency Preparedness Information Network, TDI in Silver Spring, MD, works with individuals who are deaf, hard of hearing or deaf-blind, or have other access and functional needs, in emergency and disaster preparedness. Outreach coordinator Andrew Perlman says that they stress preparedness for themselves and their families—including having batteries on hand for their devices and signing up for alerts and notifications—something that often takes awhile to catch on. Perlman says that during CEPIN trainings, instructors point out the need for these consumers to understand the role of first responders and work with them, and to also encourage people with access and functional needs to get involved in emergency planning. Especially for people who are deaf-blind, Perlman says they work with personal care attendants to get the word out about preparedness.

CEPIN also conducts training sessions with emergency responders. "One of the biggest barriers is that some emergency responders still see people with access and functional needs as liabilities," Perlman says. "In reality, they can be assets. These people have contributed many perspectives and ideas about how to assist them in emergencies," he says. Once these individuals have what they need to remain independent during emergencies and disasters, responders can focus their attention on those who really need their services. Perlman also recognizes the need for emergency responders to understand how individuals who are deaf, hard of hearing, or deaf-blind

receive information. "Since not every responder knows sign language, many jurisdictions, such as the Illinois State Police, use picture books, where people can point to whatever the need is. Or they can simply communicate by writing things down. Another issue is how to make training truly accessible."

"June 1 to November 30, is hurricane season, with many chances for thunderstorms, power outages, excessive heat, tornadoes and other dangers. In response, DC Homeland Security and Emergency Management Agency (HSEMA) Director Millicent West coordinated development of the District's Heat Plan and managed the response of District government and private sector agencies to open cooling centers," says Chief of Plans and Preparedness for HSEMA, Patrice White.

HSEMA's mission is to support and coordinate homeland security and

Also, as the central communications point during regional emergencies; HSEMA conducts assessments of resources and capabilities for emergencies; provides public awareness and outreach programs, and provides 24-hour emergency operations center capabilities. HSEMA works closely with other emergency response agencies in carrying out its mission.

Emergencies typically begin at the community level, in neighborhoods. "This summer, during a recent power outage on North Capitol Street," says White, "HSEMA partnered with District and volunteer agencies to coordinate the relocation of residents to the temporary shelter at Walker-Jones Elementary School. It is imperative for our residents to take personal responsibility for being prepared; have an emergency family plan; know their neighbors; and join HSEMA in developing Community Emergency Management Plans

(CEMPs) to ensure our neighborhoods are safe in the event of disaster. Listen to the radio, watch television or follow HSEMA on Twitter at DC\_HSEMA or on Facebook at [www.facebook.com/DCSEMA](http://www.facebook.com/DCSEMA), or visit HSEMA's preparedness site at [www.72hours.dc.gov](http://www.72hours.dc.gov) for further guidance on how to be prepared for

***"One of the biggest barriers is that some emergency responders see people with access and functional needs as liabilities," Perlman says. "In reality, they can be assets. These people have contributed many perspectives and ideas about how to assist them in emergencies."***

emergency management efforts, ensuring that the District of Columbia's all-hazards emergency operations are prepared to protect against, plan for, respond to, and recover from natural and man-made hazards. This is accomplished by:

- Developing plans and procedures to ensure emergency response and recovery capabilities for all emergencies and disasters;
- Coordinating emergency resources for emergencies and disaster incidents;
- Providing training for all emergency first responders, city employees, and the public;
- Conducting exercises; and
- Coordinating all major special events and street closings.

emergencies and learn protective actions. Also, we strongly encourage the public to register for the Alert DC Text messaging service to receive real-time emergency messages and incident information on your cell phone, computer email or PDA. Free registration is available online at <http://hsema.dc.gov/dcema/site/default.asp> Just select the Alert DC symbol on the page.

White continues, "The Community Engagement Division often holds public awareness meetings to familiarize the public about what to do when disaster strikes. While supplies last, HSEMA gives away items such as weather radios, flashlights and pillboxes to encourage residents to be person-

ally prepared by creating their own emergency kits." Call the Community Engagement Division at 202-727-6161 for more information.

Protecting lives and saving property is a fundamental principle of emergency management. In support of Mayor Vincent C. Gray's "One City" theme, HSEMA is ensuring that the revision of the District Response Plan (DRP) addresses the needs of the "whole community." We must continue to work together to coordinate our plans, prepare ourselves, our families, our work-sites, and our community for disaster," says White.

The American Red Cross of the National Capital Area ([www.redcross.org](http://www.redcross.org)) offers First Aid and CPR classes and workshops on emergency preparedness—including specifics on what items should be included in emergency kits. Jennifer Kurtinitis, the coordinator for disaster response for Montgomery County, MD, is enthusiastic about the eight functional needs trailers that the chapter was able to get through an Urban Area Security Initiative (UASI) grant from

FEMA. The trailers are sent to temporary shelters wherever they are needed. "They contain walkers, toilet raisers, ramps, raised cots, whistles, flags—anything that anyone with a medical need would use in an emergency," Kurtinitis says. "And they are replenished every month, along with undergoing routine maintenance." Kurtinitis notes that all shelters have to be accessible to people with disabilities. Montgomery County Health and Human Services nurses are being trained in how to help victims of natural disasters.

American Red Cross staff members have recently entered into a partnership with Gallaudet University, connecting with social work students about preparedness. "One of the first

things we learned is to have a certified interpreter at meetings. It's not enough to have someone who knows a bit of sign language take over this responsibility. Eventually, many of our staff will learn sign language, and we do have some video phones. Many of our volunteers help us out with that," Kurtinitis says.

When the weather is good, it's easy to forget about emergencies. But they can strike any time. Continually educate yourself about what to do, and make a plan. ■

*Carrie Smoot is a Northern Virginia freelance writer.*

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## Links:

See also the *Emergency Preparedness Section under the Community Resources TAB on the CSC homepage*

- **Community Emergency Preparedness Information Network (CEPIN) – [www.cepintdi.org](http://www.cepintdi.org)**
- **Inclusive Preparedness Center – <http://inclusivepreparedness.org>**
- **ReadyNOVA Preparedness Planners – [www.readynova.com](http://www.readynova.com)**
- **Fairfax County Office of Emergency Management – [www.fairfaxcounty.gov/oem](http://www.fairfaxcounty.gov/oem)**
- **Social Needs Registry – [www.fairfaxcounty.gov/specialneeds/socialneedsregistry.htm](http://www.fairfaxcounty.gov/specialneeds/socialneedsregistry.htm)**
- **Be Ready DC: A Guide to Family Preparedness – [http://hsema.dc.gov/dcema/frames.asp?doc=/dcema/lib/dcema/16107-Preparedness\\_Guide-Eng.pdf](http://hsema.dc.gov/dcema/frames.asp?doc=/dcema/lib/dcema/16107-Preparedness_Guide-Eng.pdf)**

# Assessing Virginia's Disability Services - 2011 Assessment of the Disability Services System in Virginia

*Reprinted with thanks from the Virginia Board for People with Disabilities website -  
www.vbpd.virginia.gov*

The Virginia Board for People with Disabilities, the Commonwealth's Developmental Disabilities (DD) Council, is pleased to provide its 2011 Assessment of the Disability Services System in Virginia. This latest edition features a new chapter largely consolidating coverage of services provided through the Medicaid public insurance program. Medicaid was covered primarily in the Community Supports chapter of previous editions, but other chapters included significant amounts of Medicaid information as well. Coverage of Information and Advocacy Resources has been reformatted and is now contained in an appendix to the assessment.

Like the previous editions, the 2011 Assessment describes disability services and supports that are primarily—but not exclusively—funded, operated, licensed, regulated, or contracted for by state agencies. For each service topic, it details eligibility requirements, how services are accessed and delivered, the types of services available, costs and payment sources, and oversight and quality assurance responsibilities. Each chapter provides longitudinal data showing trends in utilization and expenditures for specific services, as appropriate and available. A reference list that includes key websites concludes each chapter. As requested by readers of previous editions, online links to key reports and programs are also included within the body of each chapter.

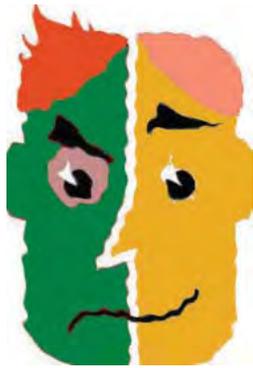
*You may download the Assessment as a single PDF, or you may download each section individually:*

**Preface and Table of Contents • Key Findings and Board Recommendations**  
**Early Intervention • Education • Employment • Medicaid**  
**Community Supports • Institutional Services • Health**  
**Community Housing • Transportation • Emergency Preparedness**  
**Appendix A: Statewide Information and Advocacy Resources**  
**Appendix B: Acronyms**  
**Index**  
**Board Membership, Staff, and Contact Information**

An audio version of the Assessment will be available on this website where it can be downloaded for listening on a computer, mp3 player, or other compatible audio device. Copies of the Assessment on CD-ROM (PDF Format) may be obtained by contacting the Board. For more information, please contact us at:

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www.vbpd.virginia.gov  
(804) 786-0016 - Voice & TTY  
(800) 846-4464 - Toll-Free, Voice & TTY  
(804) 786-1118 - Fax





# Bipolar Informational Websites

## Editor's note:

*My thanks to Mrs. Kelly Harris and her after school support group, one of whose students found a particular website – [www.healthline.com/health/bipolar-disorder](http://www.healthline.com/health/bipolar-disorder) – and they passed the information along to me. So I thought I would list other sites I have found with information about bipolar disorders. Some of these can also be found on the **Community Resources Tab** of the *Celebration Special Children* website.*

- **American Academy of Child and Adolescent Psychiatry**

Bipolar Fact sheet from website. Distributes information in an effort to promote an understanding of mental illnesses and remove the stigma associated with them.

[www.aacap.org](http://www.aacap.org)

- **The Child and Adolescent Bipolar Foundation**

Support for families raising children diagnosed with, or at risk for, early-onset bipolar disorder. Can search for support groups on this site.

[www.bpkids.org](http://www.bpkids.org)

- **Depression and Bipolar Support Alliance**

Patient-directed national organization focusing on the most prevalent mental illnesses.

[www.dbsalliance.org](http://www.dbsalliance.org)

- **Flipswitch**

Portion of the Depression and Bipolar Support Alliance website dedicated to helping teens & 20s understand depression and bipolar disorder.

[www.bpkids.org/flipswitch](http://www.bpkids.org/flipswitch)

- **Healthline.com/health/bipolar-disorder**

Portion of the Healthline website with a wealth of information devoted to bipolar symptoms, tests, treatments, etc.

[www.healthline.com/health/bipolar-disorder](http://www.healthline.com/health/bipolar-disorder)

- **Mental Health America**

The country's oldest and largest non-profit organization addressing all aspects of mental health and mental illness.

[www.nmha.org/go/bipolar](http://www.nmha.org/go/bipolar)

- **National Alliance on Mental Illness**

Bipolar Fact Sheet – NAMI's education and support programs provide relevant information, valuable insight, and the opportunity to engage in support networks.

[www.nami.org](http://www.nami.org)

- **National Institute on Mental Health**

Part of the National Institutes of Health (NIH), a component of the U.S. Department of Health and Human Services.

[www.nimh.nih.gov/health/publications/bipolar-disorder-in-children-and-adolescents/index.shtml](http://www.nimh.nih.gov/health/publications/bipolar-disorder-in-children-and-adolescents/index.shtml)

- **PsychCentral**

Informational website listing many conditions including Bipolar Disorder Fact Sheet.

<http://psychcentral.com/lib/2009/bipolar-disorder-fact-sheet/>

*The resources listed here are for informational purposes only. Inclusion does not indicate an endorsement by Celebrating Special Children (CSC). Likewise, omission of a program does not indicate disapproval of that program. CSC makes no judgment on the standards of operations of services that are listed here. ■*

Look for the next issue of *dis-Abilities Celebration Connection* to be posted during the month of October. As we continue, we will hopefully get bigger and better with lots of useful and entertaining information. Remember to send us story ideas, interesting links, and events. We can't do it without you!

## *dis-Abilities*

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